

Using Surveillance Data to Achieve Elimination

Summary of Surveillance Evaluation Conference Calls: Identifying Issues and Concerns for Further Discussion

Background: To reach the national goal of elimination of childhood lead poisoning by 2010, state and local health departments will play an essential role in identifying children who are at risk for elevated blood lead levels (EBLLs), effectively managing children with EBLLs to drastically reduce the number of children with EBLLs, and effectively targeting interventions to prevent children from being exposed to lead. Surveillance data can help childhood lead poisoning prevention programs (CLPPPs) evaluate how effectively they are identifying children with elevated blood lead levels (BLLs), reducing BLLs among children with elevated BLLs, and targeting and implementing educational efforts.

Purpose of Calls: CDC's Lead Poisoning Prevention Branch (LPPB) organized four conference calls in December 2001 to learn what CLPPPs think should be done to make childhood lead poisoning prevention data more useful for reducing BLLs and eliminating lead poisoning in their community/jurisdiction.

SUMMARY OF COMMENTS FROM CONFERENCE CALLS

The comments from the CLPPP participants were recorded and reviewed by LPPB staff. LPPB staff value the insight provided by the CLPPPs and plan to continue some of the discussions in workgroups. During the calls LPPB staff mentioned holding a surveillance meeting for a few CLPPP representatives. However, it seems a considerable amount of work could be accomplished by conference calls. LPPB plans to sponsor a surveillance meeting and ideally one that could have a representative from each CLPPP. However, no date has been set for that meeting.

Workgroups will be created and tasked to address specific issues that will help improve the quality, analysis and dissemination of the surveillance data at the national, state and local levels. The issues raised have been prioritized and the first workgroups will focus on the most pressing issues. Workgroups will have specific goals that can be achieved in a short time. After a workgroup reaches its goal, its recommendations will be made available, possibly posted on the CDC Lead website, to all CLPPPs for additional input. New workgroups may be formed to address other issues of concern. If you are especially interested in and have experience resolving some of the issues that will be addressed by any of the workgroups below, please contact the person listed as the lead.

Below is a summary of the issues CLPPP participants raised and LPPB's response.

Priority Issues Identified

1. Standards for reporting and analysis

CLPPP participants asked for assistance in developing standard definitions that could be used to improve comparability of childhood lead poisoning surveillance data across states. CLPPP participants asked for definitions for the following: case, new case, screening test, Medicaid

enrolled/eligible, paint source, screening rate, false positive, elevated test, incidence, confirmatory test, lead poisoning.

CDC Action: Data Standards Workgroup. Tim Dignam will lead a workgroup of individuals from CLPPPs to define standard case definitions for childhood lead poisoning surveillance.

2. Data Release Policy

One of the first steps in disseminating state childhood lead surveillance data is to define the criteria for when and how these data may be released. For example, there may be confidentiality issues that may require that cells be suppressed when the numbers are small. If researchers request to analyze the state surveillance data, it would be helpful to have a protocol that describes how such data may be released. Another example would be how authorship would be listed when CLPPP staff have contributed to work that is prepared for publication.

CDC Action: Data Release Workgroup. Wendy Blumenthal will lead a workgroup of individuals from CLPPPs to define how data should be reported and who can analyze state data.

3. Laboratory Reporting Issues

Reports from laboratories include a lot of fields that are blank and it takes a lot of time to go back to the laboratories and physicians to obtain missing information. The volume of tests makes it difficult to go back to providers and laboratories to obtain complete information on all reports. In addition, different forms are used for reporting and inconsistent categories are used for race/ethnicity. Obtaining missing information from private and out-of-state laboratories is more challenging for CLPPPs; reporting from laboratories outside of the state aren't as complete as reporting from in-state laboratories. Laboratories have indicated to CLPPP staff that they prefer to have one standard for reporting across the nation. Some CLPPP callers said they think getting laboratories to report basic/core information should be a CDC responsibility.

CDC Action: CDC is working with laboratories and state health departments to develop an electronic laboratory reporting (ELR) system. While this effort is still being developed it should address some of the concerns raised by CLPPP participants during these calls. ELR will use one format for all laboratory reporting across the country. This should result in participating laboratories sending electronic data rather than hardcopy reports that have to be entered. Lem Turner is working with CDC staff involved in developing ELR.

4. Facilitate networking

The need for more networking and sharing of information was clear. During the calls, some of the participants began asking other participants how they dealt with specific issues. One example was sharing computer code to help with Medicaid linking. One way LPPB could help foster sharing of information by CLPPPs is to identify topics of concern and summarize the successes of CLPPPs. This information could be posted on the CDC website and could include information on who could be contacted for more information.

CDC Action: Nikki Kilpatrick will work with CLPPPs to identify the type of information that would be most useful for sharing among staff involved in childhood lead poisoning prevention. The first step for dissemination will be to post the information on CDC's website.

5. Data Uses

CLPPP participants offered the following examples of how they are currently using their childhood lead surveillance data:

Reports - (annual lead report; annual health report; reports to health districts, county and city planners, EPSDT, and the community, quarterly EPI bulletin, on the CLPPP website)

Describe trends - (analyzed data by birth cohort; looked at prevalence over a 10-year period)

Evaluate Case Management - look at BLLs increasing and decreasing;

Develop Targeted Screening Strategy - mapping to help focus activities; assess whether the high risk kids are being screened

Target Interventions (use GIS and CBLs to look at clusters of high BLLs to target education and housing issues)

Environmental Activities (looking for homes that poison multiple children and work with EPA, provide to landlords, assess environmental outcomes)

Collaborate with university researchers - (for studies, GIS)

Share with other government agencies - with the state Medicaid agency and WIC, HUD, Section VIII Housing Administration, OSHA, Medicaid (EPSDT office, child health agency)

Improve Quality of Data - by linking with other databases such as WIC, Vital Records, data warehouse, Medicaid

Respond to Requests for Information - from child health agency and child health organizations,

CDC Action: Penn Jacobs will contact CLPPP staff to begin compiling examples of how CLPPPs are using childhood blood lead surveillance data.

6. GIS

GIS was one of the ways CLPPPs are using surveillance and other data to improve targeted screening and to evaluate the impact of childhood lead poisoning prevention activities.

CDC Action: Jerry Curtis has organized a GIS Workgroup with representatives from several CLPPPs to assess state GIS capability and needs, and to define priority areas. He will continue to work with this group. Anyone interested in joining should contact Jerry.

Other Issues Raised

Reporting All BLLs

Having laws that require that all BLLs are reported seems to help. It was noted, that passing laws to require reporting all BLLs takes a long time and must have the support of the health department bureaucracy. However, at least one CLPPP mentioned having a law, but that it is not enforced. Some CLPPP participants mentioned that reporting from managed care organizations is poor.

CDC Action: LPPB will work with individual CLPPPs that are not reporting all blood lead levels because many CLPPPs are already reporting all blood lead levels.

Medicaid linking

Many challenges were noted by CLPPP participants concerning matching lead data with Medicaid data to identify children who are enrolled in Medicaid. Some CLPPPs have not been able to obtain access to Medicaid data. Some of the reasons include lack of interest from the state Medicaid agency in matching with lead data; inadequate computer expertise/support to provide Medicaid data to CLPPPs; and concerns that physicians may discriminate against patients if they know the child is on Medicaid. Other CLPPPs have access to Medicaid data, however, the Medicaid data may be difficult to use. For example, CLPPPs may have to manually review non-matches to see if they just aren't matching because of spelling errors; and there may be problems with the way Medicaid data are coded.

CDC Action: LPPB staff will be assigned to work on this later this year.

Data Quality

Missing information is common. At least one CLPPP prioritizes the fields that are most important to collect. Another CLPPP focuses on obtaining complete information for cases. Other CLPPPs noted that they have linked their childhood lead surveillance data with other databases such as immunization registries, Medicaid, birth certificate data to improve the quality and completeness of their surveillance data.

CDC Action: LPPB staff will be assigned to work on this later this year.
